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## Parenting a child with chronic illness as they transition into adulthood

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**Title: Parenting a child with chronic illness as they transition into adulthood: A systematic review and thematic synthesis of parents' experiences**

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**Author contributions:** All authors contributed to the review design and analysis of papers. GH conducted the searches. GH and AF conducted data extraction and coding. GH drafted the manuscript. All authors revised the manuscript and approved the final version.

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## **Parenting a child with chronic illness as they transition into adulthood: A systematic review and thematic synthesis of parents' experiences**

### **Abstract**

**Objective:** To understand how parents view and experience their role as their child with a long-term **physical health** condition transitions to adulthood and adult healthcare services. **Methods:** Five databases were systematically searched for qualitative articles examining parents' views and experiences of their child's healthcare transition. Papers were quality assessed and thematically synthesised. **Results:** Thirty-two papers from six countries, spanning a 17-year period were included. Long-term conditions were diverse. Findings indicated that parents view their child's progression toward self-care as an incremental process which they seek to facilitate through up-skilling them in self-management practices. Parental perceptions of their child's readiness, wellness, competence and long-term condition impacted on the child's progression to healthcare autonomy. A lack of transitional healthcare and differences between paediatric and adult services served as barriers to effective transition. Parents were required to adjust their role, responsibilities and behaviour to support their child's growing independence. **Conclusion:** Parents **can** be key facilitators of their child's healthcare transition, supporting them to become experts in their own condition and care. To do so, they require clarification on their role and support from **service** providers. **Practice Implications:** Interventions are needed which address the transitional care needs of parents as well as young people.

**Keywords:** Parents; Child health; Long-term conditions; Transition; Qualitative research

## Parenting a child with chronic illness as they transition into adulthood: A systematic review and thematic synthesis of parents' experiences

### 1. Introduction

Long-term physical health conditions (LTCs) affect significant and increasing numbers of adolescents in the UK [{ ADDIN EN.CITE

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Health</publisher><urls></urls></record></Cite></EndNote>}. Advances in treatment/technology mean that these young people are now more likely than ever to reach adulthood [{ ADDIN EN.CITE <EndNote><Cite><Author>Kennedy</Author><Year>2007</Year><RecNum>4384</RecNum><DisplayText><style face="superscript">2</style></DisplayText><record><rec-number>4384</rec-number><foreign-keys><key app="EN" db-id="exwx9f9epzvv52ezrvippa79z22d9pawfes" timestamp="1408360442">4384</key></foreign-keys><ref-type name="Journal Article">17</ref-type><contributors><authors><author>Kennedy, A.</author><author>Sloman, F.</author><author>Douglass, J. A.</author><author>Sawyer, S. M.</author></authors></contributors><titles><title>Young people with chronic illness: the approach to transition </title><secondary-title>Internal Medicine Journal </secondary-

title></titles><periodical><full-title>Internal Medicine Journal</full-title></periodical><pages>555–560</pages><number>37</number><dates><year>2007</year></dates><urls></urls></record></Cite></EndNote>}. This will at some point, require them to assume a greater degree of independence and self-care than previously encountered [{ ADDIN EN.CITE <EndNote><Cite><Author>Dovey-Pearce</Author><Year>2013</Year><RecNum>4403</RecNum><DisplayText><style

face="superscript">3</style></DisplayText><record><rec-number>4403</rec-number><foreign-keys><key app="EN" db-id="exwx9f9epzvv52ezrvippa79z22d9pawfes" timestamp="1408370240">4403</key></foreign-keys><ref-type name="Journal Article">17</ref-type><contributors><authors><author>Dovey-Pearce, G.</author><author>Christie, D.</author></authors></contributors><titles><title>Transition in diabetes: young people move on we should too</title><secondary-title>Paediatrics and Child Health</secondary-title></titles><periodical><full-title>Paediatrics and Child Health</full-title></periodical><pages>174-

179</pages><volume>23</volume><number>4</number><dates><year>2013</year></dates><urls></urls></record></Cite></EndNote>}], in addition to transferring from paediatric to adult services for ongoing healthcare [{ ADDIN EN.CITE

<EndNote><Cite><Author>Rutishauser</Author><Year>2011</Year><RecNum>248</RecNum><DisplayText><style face="superscript">4</style></DisplayText><record><rec-number>248</rec-number><foreign-keys><key app="EN" db-id="exwx9f9epzvv52ezrvippa79z22d9pawfes" timestamp="1397133593">248</key></foreign-keys><ref-type name="Journal Article">17</ref-type><contributors><authors><author>Rutishauser, C.</author><author>Akré,

C./author><author>Suris, J-C./author></authors></contributors><titles><title>Transition from pediatric to adult health care: expectations of adolescents with chronic disorders and their parents</title><secondary-title>European Journal of Pediatrics</secondary-title></titles><periodical><full-title>European Journal of Pediatrics</full-title></periodical><pages>865-871</pages><volume>170</volume><dates><year>2011</year></dates><urls></urls></record></Cite></EndNote>}}. The need for effective transitional care and the benefits this provides in terms of maintaining engagement with healthcare throughout the life course and improving health outcomes is well established [{ ADDIN EN.CITE <EndNote><Cite><Author>McDonagh</Author><Year>2010</Year><RecNum>4410</RecNum><DisplayText><style face="superscript">5</style></DisplayText><record><rec-number>4410</rec-number><foreign-keys><key app="EN" db-id="exwx9f9epzvv52ezrvippa79z22d9pawfes" timestamp="1408372083">4410</key></foreign-keys><ref-type name="Journal Article">17</ref-type><contributors><authors><author>McDonagh, J. E.</author><author>Kelly, D. A.</author></authors></contributors><titles><title>The challenges and opportunities for transitional care research</title><secondary-title>Pediatric Transplantation </secondary-title></titles><periodical><full-title>Pediatric Transplantation</full-title></periodical><pages>688–700</pages><volume>14</volume><dates><year>2010</year></dates><urls></urls></record></Cite></EndNote>}}. However, transition cannot be conceptualised as young person-only phenomenon. Parents and adolescents together create the emotional environment necessary for the adolescent's adaptation to the demands of young adulthood [{ ADDIN EN.CITE <EndNote><Cite><Author>Bronfenbrenner</Author><Year>1979</Year><RecNum>4466</RecNum><DisplayText><style face="superscript">6</style></DisplayText><record><rec-number>4466</rec-number><foreign-keys><key app="EN" db-id="exwx9f9epzvv52ezrvippa79z22d9pawfes" timestamp="1430234549">4466</key></foreign-keys><ref-type name="Book">6</ref-type><contributors><authors><author>Bronfenbrenner, U.</author></authors></contributors><titles><title>The Ecology of Human Development.</title></titles><dates><year>1979</year></dates><pub-location>Cambridge, MA:</pub-location><publisher>Harvard University Press</publisher><urls></urls></record></Cite></EndNote>},{ ADDIN EN.CITE <EndNote><Cite><Author>Excellence</Author><Year>2016</Year><RecNum>4565</RecNum><DisplayText><style face="superscript">7</style></DisplayText><record><rec-number>4565</rec-number><foreign-keys><key app="EN" db-id="exwx9f9epzvv52ezrvippa79z22d9pawfes" timestamp="1459770516">4565</key></foreign-keys><ref-type name="Patent">25</ref-type><contributors><authors><author>National Institute for Health and Care Excellence</author></authors><secondary-authors><author>nice.org.uk/guidance/ng43</author></secondary-authors></contributors><titles><title>Transition from children's to adults' services for young people using health or social care services</title></titles><dates><year>2016</year></dates><urls></urls></record></Cite></EndNote>}}. Healthcare transition therefore also requires parents to adjust their care giving role, gradually relinquishing control of their child's LTC and supporting progression to young person autonomy [{ ADDIN EN.CITE { ADDIN EN.CITE.DATA }}]. Studies examining the role of family members during the transitional period [{ ADDIN EN.CITE { ADDIN EN.CITE.DATA }}] suggest parents face a range of new care challenges associated with their and their child's development, including adaptation to a

changing role, allocation of treatment responsibilities and anxiety regarding their child's illness trajectory [{ ADDIN EN.CITE

<EndNote><Cite><Author>Gannoni</Author><Year>2010</Year><RecNum>4387</RecNum><DisplayText><style face="superscript">12</style></DisplayText><record><rec-number>4387</rec-number><foreign-keys><key app="EN" db-id="exwx9f9epzvv52ezrvippa79z22d9pawfes" timestamp="1408362561">4387</key></foreign-keys><ref-type name="Journal Article">17</ref-type><contributors><authors><author>Gannoni, A. F. </author><author>Shute, R. H. </author></authors></contributors><titles><title>Parental and child perspectives on adaptation to childhood chronic illness: A qualitative study</title><secondary-title>Clinical Child Psychology and Psychiatry</secondary-title></titles><periodical><full-title>Clinical Child Psychology and Psychiatry</full-title></periodical><pages>39–53</pages><volume>15</volume><number>1</number><dates><year>2010</year></dates><urls></urls></record></Cite></EndNote>}}].

Despite recognition of the systemic nature of transition [{ ADDIN EN.CITE

<EndNote><Cite><Author>Excellence</Author><Year>2016</Year><RecNum>4565</RecNum><DisplayText><style face="superscript">7</style></DisplayText><record><rec-number>4565</rec-number><foreign-keys><key app="EN" db-id="exwx9f9epzvv52ezrvippa79z22d9pawfes" timestamp="1459770516">4565</key></foreign-keys><ref-type name="Patent">25</ref-type><contributors><authors><author>National Institute for Health and Care Excellence</author></authors><secondary-authors><author>nice.org.uk/guidance/ng43</author></secondary-authors></contributors><titles><title>Transition from children's to adults' services for young people using health or social care services</title></titles><dates><year>2016</year></dates><urls></urls></record></Cite></EndNote>}}] and the effect of this developmental phase on shifting roles within family systems, previous

reviews have focused on the perspectives of patients [{ ADDIN EN.CITE { ADDIN EN.CITE.DATA } }], transitional models [{ ADDIN EN.CITE

<EndNote><Cite><Author>Watson</Author><Year>2011</Year><RecNum>4389</RecNum><DisplayText><style face="superscript">16 17</style></DisplayText><record><rec-number>4389</rec-number><foreign-keys><key app="EN" db-id="exwx9f9epzvv52ezrvippa79z22d9pawfes" timestamp="1408366391">4389</key></foreign-keys><ref-type name="Journal Article">17</ref-type><contributors><authors><author>Watson, R. </author><author>Parr, J. R. </author><author>Joyce, C. </author><author>May, C. </author><author>Le Couteur, A. S. </author></authors></contributors><titles><title>Models of transitional care for young people with complex health needs: a scoping review</title><secondary-title>Child: care, health and development</secondary-title></titles><periodical><full-title>Child: care, health and development</full-title></periodical><pages>780–791</pages><volume>37</volume><number>6</number><dates><year>2011</year></dates><urls></urls></record></Cite><Cite><Author>Kime</Author><Year>2013</Year><RecNum>4402</RecNum><record><rec-number>4402</rec-number><foreign-keys><key app="EN" db-id="exwx9f9epzvv52ezrvippa79z22d9pawfes" timestamp="1408370040">4402</key></foreign-keys><ref-type name="Report">27</ref-type><contributors><authors><author>Kime, N.</author><author>Bagnall, A. M.</author><author>Day, R. </author></authors></contributors><titles><title>Systematic review of transition models for young

people with long-term conditions: A report for NHS

Diabetes

te>]] and healthcare practices [{ ADDIN EN.CITE

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</author><author>Ullman, R. </author><author>Lewis, S. </author><author>Mathes, L.

</author><author>Griffiths, P. </author></authors></contributors><titles><title>Good practices

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evidence</title><secondary-title>Child: Care, Health & Development</secondary-

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title></periodical><pages>439–

452</pages><volume>30</volume><number>5</number><dates><year>2004</year></dates><urls>

</urls></record></Cite><Cite><Author>Crowley</Author><Year>2011</Year><RecNum>226</Rec

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</secondary-title></titles><periodical><full-title>Archives of Disease in Childhood</full-

title></periodical><pages>548–

553</pages><volume>96</volume><dates><year>2011</year></dates><urls></urls></record></Cit

e></EndNote>]]. Reviews have been carried out on the experience of parenting a child with a LTC [{

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<EndNote><Cite><Author>Coffey</Author><Year>2006</Year><RecNum>4461</RecNum><DisplayT

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Metasynthesis</title><secondary-title>Pediatric Nursing</secondary-title></titles><periodical><full-

title>Pediatric Nursing</full-title></periodical><pages>51-

59</pages><volume>32</volume><number>1</number><dates><year>2006</year></dates><urls>

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children and adolescents with chronic illness [{ ADDIN EN.CITE

<EndNote><Cite><Author>Eccleston</Author><Year>2012</Year><RecNum>4388</RecNum><Displ

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type><contributors><authors><author>Eccleston, C. </author><author>Palermo, T. M.

</author><author>Fisher, E. </author><author>Law, E.

</author></authors></contributors><titles><title>Psychological interventions for parents of

children and adolescents with chronic illness.

</title><secondary-title>Cochrane Database of Systematic Reviews</secondary-title></titles><periodical><full-title>Cochrane Database of Systematic Reviews</full-title></periodical><volume>8</volume><dates><year>2012</year></dates><urls></urls></record></Cite><Cite><Author>Morawska</Author><Year>2015</Year><RecNum>4462</RecNum><record><rec-number>4462</rec-number><foreign-keys><key app="EN" db-id="exwx9f9epzv52ezrvippa79z22d9pawfes" timestamp="1430232904">4462</key></foreign-keys><ref-type name="Journal Article">17</ref-type><contributors><authors><author>Morawska, A. </author><author>Calam, R. </author><author>Fraser, J. </author></authors></contributors><titles><title>Parenting interventions for childhood chronic illness: A review and recommendations for intervention design and delivery</title><secondary-title>Journal of Child Health Care</secondary-title></titles><periodical><full-title>Journal of Child Health Care</full-title></periodical><pages>5-17</pages><volume>19</volume><number>1</number><dates><year>2015</year></dates><urls></urls></record></Cite></EndNote>]], however, these do not consider the experience of parenting a child with a chronic condition during their transition to adulthood and adult-services.

It is important to understand how parents experience their child's transition to adulthood because how parents manage and cope with their own change in roles and responsibilities will likely impact on both their child's transition to independent self-care as well as their own psychological well-being. Understanding the challenges that parents face, from their perspective, will further indicate support needs.

## 1.1 Aim & Objectives

This review aimed to collect and synthesise primary research relating to how parents understand and experience their role as their child with a LTC transitions to adulthood and adult healthcare services. The objectives were to: (a) understand how parents experience their care-giving role in relation to supporting their child's transition to adulthood/services; (b) understand how parents experience their care-giving role in relation to their own well-being; (c) make recommendations regarding how healthcare providers can support parents during their child's transition.

## 2. Methods

The review adopted a systematic search methodology in accordance with PRISMA guidance [ { ADDIN EN.CITE

<EndNote><Cite><Author>Moher</Author><Year>2009</Year><RecNum>4566</RecNum><DisplayText><style face="superscript">23</style></DisplayText><record><rec-number>4566</rec-number><foreign-keys><key app="EN" db-id="exwx9f9epzv52ezrvippa79z22d9pawfes" timestamp="1459770921">4566</key></foreign-keys><ref-type name="Journal Article">17</ref-type><contributors><authors><author>Moher, D.</author><author>Liberati, A.</author><author>Tetzlaff, J.</author><author>Altman, D.G.</author><author>PRISMA Group</author></authors></contributors><titles><title>Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. </title><secondary-title>British Medical Journal</secondary-title></titles><periodical><full-title>British Medical Journal</full-title></periodical><pages>b2535-



6</pages><volume>339</volume><dates><year>2009</year></dates><urls></urls></record></Cite></EndNote>}} and followed the analytic procedure for 'thematic' synthesis [{ ADDIN EN.CITE <EndNote><Cite><Author>Thomas</Author><Year>2008</Year><RecNum>4463</RecNum><DisplayText><style face="superscript">24</style></DisplayText><record><rec-number>4463</rec-number><foreign-keys><key app="EN" db-id="exwx9f9epzvv52ezrvippa79z22d9pawfes" timestamp="1430233207">4463</key></foreign-keys><ref-type name="Journal Article">17</ref-type><contributors><authors><author>Thomas, J.</author><author>Harden, A.</author></authors></contributors><titles><title>Methods for the thematic synthesis of qualitative research in systematic reviews. </title><secondary-title>BMC Medical Research Methodology</secondary-title></titles><periodical><full-title>BMC Medical Research Methodology</full-title></periodical><volume>8</volume><number>45</number><dates><year>2008</year></dates><urls></urls></record></Cite></EndNote>}}].

## 2.1 Eligibility Criteria

To be included, papers had to report qualitative findings of primary research exploring parents' understanding and experiences of their role as their child with a LTC transitioned to adulthood and/or adult services. Parents included mothers, fathers and other primary care-givers (e.g. grandparents) of young people with long-term physical health conditions. In accordance with the WHO definition, an age range for young people of 10-24 years was stipulated. LTCs were defined as physical "illnesses that are prolonged, do not resolve spontaneously, and are rarely cured completely" [{ ADDIN EN.CITE <EndNote><Cite><Author>US Centers for Disease Control and Prevention</Author><Year>2003</Year><RecNum>4567</RecNum><DisplayText><style face="superscript">25</style></DisplayText><record><rec-number>4567</rec-number><foreign-keys><key app="EN" db-id="exwx9f9epzvv52ezrvippa79z22d9pawfes" timestamp="1459771473">4567</key></foreign-keys><ref-type name="Journal Article">17</ref-type><contributors><authors><author>US Centers for Disease Control and Prevention, National Center for Chronic Disease Prevention and Health Promotion.</author></authors></contributors><titles><title>About chronic disease: definition, overall burden, and cost effectiveness of prevention.</title></titles><dates><year>2003</year></dates><urls><related-urls><url>www.cdc.gov/nccdphp/about.htm</url></related-urls></urls></record></Cite></EndNote>}}]. This meant conditions that require on-going clinical care and self-management, for which medications are critical, and require follow-up at clinic. Examples include diabetes mellitus and cystic fibrosis. As the review focused on physical health, mental health conditions such as anxiety and depression were excluded, as were learning difficulties such as autism. Papers reporting studies with mixed samples (e.g. perspectives of young people, parents and professionals), were included if data pertaining to parents were reported separately or could be separated by the reviewers. Studies with wholly young person or professional samples were excluded. No limits were placed on the year of publication; only studies reported in English were included.

## 2.2 Systematic Search

Five electronic databases (Medline; CINAHL; EMBASE; PsycINFO; HMIC) were systematically searched to identify potentially eligible articles from inception until June 2015. Google Scholar was used to search for grey literature. A comprehensive search strategy was developed to include a combination of free text and index terms. Key search terms included parents; transition; hospital; chronic illness. The Boolean operator 'OR' was used to combine synonymous keywords, with 'AND' used to combine key concepts (figure 1). Articles identified by the electronic searches were downloaded into a reference management database and duplicates removed. Remaining citations were screened by the first author by title and abstract. Articles that clearly did not meet the inclusion criteria were excluded and all other possible relevant citations retrieved as full-text copies. All authors independently assessed the eligibility of retrieved full-text papers against the inclusion criteria. They then met to discuss their assessments. Uncertainties were discussed until consensus agreed. References of all included studies were hand-searched for additional articles which were assessed for inclusion in the same way.

### 2.3 Critical Appraisal of the Included Studies

Included papers were quality assessed using the Critical Appraisal Skills Program [{ ADDIN EN.CITE <EndNote><Cite><Author>CASP</Author><Year>2014</Year><RecNum>4464</RecNum><DisplayText><style face="superscript">26</style></DisplayText><record><rec-number>4464</rec-number><foreign-keys><key app="EN" db-id="exwx9f9epzvv52ezrvippa79z22d9pawfes" timestamp="1430233805">4464</key></foreign-keys><ref-type name="Web Page">12</ref-type><contributors><authors><author>CASP</author></authors></contributors><titles><title>Critical Appraisal Skills Programme (CASP) Qualitative Research Checklist CASP Checklists</title></titles><dates><year>2014</year></dates><urls><related-urls><url>http://media.wix.com/ugd/dded87\_29c5b002d99342f788c6ac670e49f274.pdf</url></related-urls></urls></record></Cite></EndNote>}. Quality assessment was carried out by the first author and a subset of papers checked by a second author. Studies of all quality were included with the quality of studies taken into consideration during data synthesis [{ ADDIN EN.CITE <EndNote><Cite><Author>Carroll</Author><Year>2012</Year><RecNum>4562</RecNum><DisplayText><style face="superscript">27</style></DisplayText><record><rec-number>4562</rec-number><foreign-keys><key app="EN" db-id="exwx9f9epzvv52ezrvippa79z22d9pawfes" timestamp="1458034699">4562</key></foreign-keys><ref-type name="Journal Article">17</ref-type><contributors><authors><author>Carroll, C.</author><author>Booth, A.</author><author>Lloyd-Jones, M. </author></authors></contributors><titles><title>Should We Exclude Inadequately Reported Studies From Qualitative Systematic Reviews? An Evaluation of Sensitivity Analyses in Two Case Study Reviews</title><secondary-title>Qualitative Health Research</secondary-title></titles><periodical><full-title>Qualitative Health Research</full-title></periodical><pages>1425-1434</pages><volume>22</volume><number>10</number><dates><year>2012</year></dates><urls></urls></record></Cite></EndNote>}.

### 2.4 Data extraction

Studies were read before data were extracted and recorded. As well as basic study information, all text presented within the findings/results sections of each included article were extracted. This included data relating to key themes and concepts as expressed by the participants and by the

authors, using a pre-prepared form. Data were then imported into NVivo version 10 to support coding and quotation retrieval. The corresponding author of included studies was contacted to obtain further information where necessary.

## 2.5 Data synthesis

Data were synthesised thematically [{ ADDIN EN.CITE <EndNote><Cite ExcludeAuth="1"><Author>Thomas</Author><Year>2008</Year><RecNum>4463</RecNum><DisplayText><style face="superscript">24</style></DisplayText><record><rec-number>4463</rec-number><foreign-keys><key app="EN" db-id="exwx9f9epzv52ezrvippa79z22d9pawfes" timestamp="1430233207">4463</key></foreign-keys><ref-type name="Journal Article">17</ref-type><contributors><authors><author>Thomas, J.</author><author>Harden, A.</author></authors></contributors><titles><title>Methods for the thematic synthesis of qualitative research in systematic reviews. </title><secondary-title>BMC Medical Research Methodology</secondary-title></titles><periodical><full-title>BMC Medical Research Methodology</full-title></periodical><volume>8</volume><number>45</number><dates><year>2008</year></dates><urls></urls></record></Cite></EndNote>}]. This method was selected as it provides a systematic and transparent approach which facilitates the production of rich and interpretive, yet data-driven themes, in order to broaden conceptual understandings of a particular phenomenon. Thematic synthesis has three stages: (1) coding of text; (2) development of 'descriptive themes'; and (3) generation of 'analytical themes'. While the development of descriptive themes remains 'close' to primary studies, analytical themes represent a stage of interpretation whereby the reviewers 'go beyond' primary studies, generating new interpretive constructs or explanations.

Inductive coding was carried out across the data set, independently by two authors according to its meaning and content [24]. Codes were then discussed with the third author and a coding frame agreed upon. This was subsequently applied to the findings of all included studies. Related codes were grouped together and labelled to form descriptive themes and a summary of each theme written. The final step of analysis, moving 'beyond' a thematic summary of included studies, was achieved by grouping and developing the descriptive themes generated from our inductive analysis to address the review objectives. This involved interpretative work by all authors, using the coded data set to understand how parents experience their care-giving role in relation to a) supporting their child's transition and b) their own well-being and c) to make recommendations for healthcare providers. During this process, new, analytical themes were generated which inferred implications for service provision from parents' descriptions of their lived experience. Here we present the analytic themes that were generated from our descriptive themes (see table X).

Trustworthiness was maintained using a number of strategies including keeping a clear and transparent audit trail, maintaining a reflexive approach, and discussing emerging understandings within a research team. We were aware that our position as health and social psychologists with training and experience in qualitative health services research would inevitably influence our interpretations. We therefore strived to remain open to unexpected discoveries by consciously reflecting on our knowledge and experience, critically appraising our individual and group level interpretations and discussing alternative explanations. It was through this process that we managed

to agree on categories in which our various interpretations fit and that would contribute to the existing knowledge base in parenting and transitional care.

### 3. Results

#### 3.1 Systematic search

1966 articles were retrieved for assessment against the inclusion criteria with 32 papers included in the review (figure 2). Papers presented qualitative data on parents' views and experiences of their child's healthcare transition in a variety of LTCs (asthma, arthritis, cancer, cystic fibrosis, congenital heart disease, cerebral palsy, diabetes, epilepsy, Marfan syndrome, sickle cell disease and spina bifida). Studies were conducted across six countries (Switzerland, UK, Canada, USA, Australia and Netherlands) over a 17-year period (1997-2014) using a variety of qualitative data collection and analysis methods (table 1).

#### 3.2 Quality appraisal

All studies were assessed as having a clear statement of aims, with an appropriate research design and methodology for addressing those aims. Only one paper discussed issues of reflexivity. This is important for considering whether and how the researcher/s might have impacted on the research outcomes. The majority of papers presented an appropriate recruitment strategy with data analysis that was judged to be sufficiently rigorous, providing a clear statement of findings and a valuable contribution to the research area (table 2).

#### 3.3 Synthesis findings

Findings regarding parenting a child with a chronic illness as they transition into adulthood and adult services were generally similar across LTCs with some differences relating to the impact of the condition and treatment on the family's life and child's future. Findings that contributed to explaining parents' understanding and experience of their role during their child's healthcare transition were captured in eight themes, grouped to address the first two review objectives: views on transition; factors affecting child autonomy; preparation for healthcare transition; service provision; young person condition management; parents' experiences of their child's transition; parental transition; and impact of the LTC on the family (table 3). Each theme is briefly described with exemplar data extracts provided in table 4. Findings were then used to address the third objective, making recommendations for service providers, which is presented within the practice implications.

#### 3.4 Understanding how parents experience their care-giving role in relation to supporting their child's transition to adulthood/services

##### 3.4.1 Views on transition

In most studies, independence-building, including transition toward self-management was regarded as "a positive social value" [

<EndNote><Cite><Author>Allen</Author><Year>2011</Year><RecNum>4412</RecNum><Suffix>`,  
p.997</Suffix><DisplayText><style face="superscript">28,  
p.997</style></DisplayText><record><rec-number>4412</rec-number><foreign-keys><key

app="EN" db-id="exwx9f9epzv52ezrvippa79z22d9pawfes" timestamp="1408372714">4412</key></foreign-keys><ref-type name="Journal Article">17</ref-type><contributors><authors><author>Allen, D. </author><author>Channon, S, </author><author>Lowes, L. </author><author>Atwell, C. </author><author>Lane, C. </author></authors></contributors><titles><title>Behind the scenes: the changing roles of parents in the transition from child to adult diabetes service</title><secondary-title>Diabetic Medicine</secondary-title></titles><periodical><full-title>Diabetic Medicine</full-title></periodical><pages>994–1000</pages><volume>28</volume><dates><year>2011</year></dates><urls></urls></record></Cite></EndNote>}}; something parents viewed as important and were motivated to support their child to develop. Achieving healthcare independence was understood as an incremental and negotiated process of gradually transferring responsibility for self-care in accordance with other increases in responsibility unrelated to the child’s health condition (e.g. staying away from home). Moving from childhood to adulthood was therefore characterised as having a number of different transitions (e.g. in healthcare systems, education). Healthcare transition was perceived as a process of mediated condition management; moving “forwards and backwards along the continuum” [{ ADDIN EN.CITE <EndNote><Cite><Author>Williams</Author><Year>2007</Year><RecNum>240</RecNum><Suffix>`, p.2146</Suffix><DisplayText><style face="superscript">10, p.2146</style></DisplayText><record><rec-number>240</rec-number><foreign-keys><key app="EN" db-id="exwx9f9epzv52ezrvippa79z22d9pawfes" timestamp="1397039137">240</key></foreign-keys><ref-type name="Journal Article">17</ref-type><contributors><authors><author>Williams, B.</author><author>Mukhopadhyay, S. </author><author>Dowell, J. </author><author>Coyle, J. </author></authors></contributors><titles><title>From child to adult: An exploration of shifting family roles and responsibilities in managing physiotherapy for cystic fibrosis</title><secondary-title>Social Science & Medicine</secondary-title></titles><periodical><full-title>Social Science & Medicine</full-title></periodical><pages>2135–2146</pages><dates><year>2007</year></dates><urls></urls></record></Cite></EndNote>}} of young person and parental management, with parents stepping in to provide respite during times of stress or episodes of illness. The transition process was activated consciously following triggers such as parents being at work or child leaving home, or unconsciously in accordance with other “developmental considerations” [{ ADDIN EN.CITE <EndNote><Cite><Author>Allen</Author><Year>2011</Year><RecNum>4412</RecNum><Suffix>`, p.997</Suffix><DisplayText><style face="superscript">28, p.997</style></DisplayText><record><rec-number>4412</rec-number><foreign-keys><key app="EN" db-id="exwx9f9epzv52ezrvippa79z22d9pawfes" timestamp="1408372714">4412</key></foreign-keys><ref-type name="Journal Article">17</ref-type><contributors><authors><author>Allen, D. </author><author>Channon, S, </author><author>Lowes, L. </author><author>Atwell, C. </author><author>Lane, C. </author></authors></contributors><titles><title>Behind the scenes: the changing roles of parents in the transition from child to adult diabetes service</title><secondary-title>Diabetic Medicine</secondary-title></titles><periodical><full-title>Diabetic Medicine</full-title></periodical><pages>994–

1000</pages><volume>28</volume><dates><year>2011</year></dates><urls></urls></record></Cite></EndNote>}}].

### 3.4.2 Factors affecting child autonomy

Several factors influenced the child's autonomy acquisition in relation to the management of their LTC. These included parents' perceptions of their child's "developmental readiness" [{ ADDIN EN.CITE

<EndNote><Cite><Author>Schilling</Author><Year>2006</Year><RecNum>4521</RecNum><Suffix>', p.419</Suffix><DisplayText><style face="superscript">29, p.419</style></DisplayText><record><rec-number>4521</rec-number><foreign-keys><key app="EN" db-id="exwx9f9epzvv52ezrvippa79z22d9pawfes" timestamp="1451921635">4521</key></foreign-keys><ref-type name="Journal Article">17</ref-type><contributors><authors><author>Schilling, L. S. </author><author>Knafl, K. A. </author><author>Grey, M. </author></authors></contributors><titles><title>Changing Patterns of Self-Management in Youth with Type I Diabetes</title><secondary-title>Journal of Pediatric Nursing</secondary-title></titles><periodical><full-title>Journal of Pediatric Nursing</full-title></periodical><pages>412-424</pages><volume>21</volume><number>6</number><dates><year>2006</year></dates><urls></urls></record></Cite></EndNote>}}], including beliefs about their child's "overall maturity and sense of responsibility" [{ ADDIN EN.CITE

<EndNote><Cite><Author>Buford</Author><Year>2004</Year><RecNum>238</RecNum><Suffix>', p.9</Suffix><DisplayText><style face="superscript">30, p.9</style></DisplayText><record><rec-number>238</rec-number><foreign-keys><key app="EN" db-id="pt5wps9zupfdv5er0w9x0pz6aee2ds2a92ax" timestamp="1405430531">238</key></foreign-keys><ref-type name="Journal Article">17</ref-type><contributors><authors><author>Buford, T. A.</author></authors></contributors><titles><title>Transfer of asthma management responsibility from parents to their school-age children</title><secondary-title>Journal of Pediatric Nursing</secondary-title></titles><periodical><full-title>Journal of Pediatric Nursing</full-title></periodical><pages>3-13</pages><volume>19</volume><number>1</number><dates><year>2004</year></dates><isbn>08825963</isbn><urls></urls></record></Cite></EndNote>}}], their emotional stability and capacity to self-care. Reaching a point of readiness was considered individual to each child and depended on parental understanding of their child's competence and motivation to carry out self-management tasks such as medication administration, symptom monitoring and self-advocacy. This in turn was linked to parental trust in their child to be responsible for their condition, that is, how much they believed their child would adhere to their treatment regimen and not endanger themselves by engaging in risky behaviours. In addition, "stability of the young person's condition" [{ ADDIN EN.CITE

<EndNote><Cite><Author>Newbould</Author><Year>2008</Year><RecNum>4522</RecNum><Suffix>', p.121</Suffix><DisplayText><style face="superscript">31, p.121</style></DisplayText><record><rec-number>4522</rec-number><foreign-keys><key app="EN" db-id="exwx9f9epzvv52ezrvippa79z22d9pawfes" timestamp="1451922830">4522</key></foreign-keys><ref-type name="Journal Article">17</ref-type><contributors><authors><author>Newbould, J. </author><author>Smith, F. </author><author>Francis, S-A.</author></authors></contributors><titles><title>'I'm fine doing it

on my own': partnerships between young people and their parents in the management of medication for asthma and diabetes</title><secondary-title>Journal of Child Health Care</secondary-title></titles><periodical><full-title>Journal of Child Health Care</full-title></periodical><pages>116–128</pages><volume>12</volume><number>2</number><dates><year>2008</year></dates><urls></urls></record></Cite></EndNote>}} impacted on when transition to self-care was encouraged and how management tasks were shared. Generally, transition to self-care was seen to need to happen during a time of “perceived wellness” [{ ADDIN EN.CITE <EndNote><Cite><Author>Williams</Author><Year>2007</Year><RecNum>240</RecNum><Suffix>`, p.2140</Suffix><DisplayText><style face="superscript">10, p.2140</style></DisplayText><record><rec-number>240</rec-number><foreign-keys><key app="EN" db-id="exwx9f9epzv52ezrvippa79z22d9pawfes" timestamp="1397039137">240</key></foreign-keys><ref-type name="Journal Article">17</ref-type><contributors><authors><author>Williams, B.</author><author>Mukhopadhyay, S.</author><author>Dowell, J. </author><author>Coyle, J.</author></authors></contributors><titles><title>From child to adult: An exploration of shifting family roles and responsibilities in managing physiotherapy for cystic fibrosis</title><secondary-title>Social Science & Medicine</secondary-title></titles><periodical><full-title>Social Science & Medicine</full-title></periodical><pages>2135–2146</pages><dates><year>2007</year></dates><urls></urls></record></Cite></EndNote>}}].

### 3.4.3 Preparation for healthcare transition

Strategies used to prepare young people for assuming healthcare autonomy included parents encouraging and supporting their child to self-care, explaining and allowing their child to “experience the consequence of their actions” [{ ADDIN EN.CITE <EndNote><Cite><Author>Buford</Author><Year>2004</Year><RecNum>238</RecNum><Suffix>`, p.10</Suffix><DisplayText><style face="superscript">30, p.10</style></DisplayText><record><rec-number>238</rec-number><foreign-keys><key app="EN" db-id="pt5wps9zupfdv5er0w9x0pz6aee2ds2a92ax" timestamp="1405430531">238</key></foreign-keys><ref-type name="Journal Article">17</ref-type><contributors><authors><author>Buford, T. A.</author></authors></contributors><titles><title>Transfer of asthma management responsibility from parents to their school-age children</title><secondary-title>Journal of Pediatric Nursing</secondary-title></titles><periodical><full-title>Journal of Pediatric Nursing</full-title></periodical><pages>3–13</pages><volume>19</volume><number>1</number><dates><year>2004</year></dates><isbn>08825963</isbn><urls></urls></record></Cite></EndNote>}}], modelling self-care behaviours, monitoring condition management and prompting treatment administration. Parents in several studies discussed actively teaching their children self-management skills including condition and treatment management, self-advocacy and “self-surveillance” of bodily symptoms [{ ADDIN EN.CITE <EndNote><Cite><Author>Giarelli</Author><Year>2008</Year><RecNum>1080</RecNum><Suffix>`, p.446</Suffix><DisplayText><style face="superscript">32, p.446</style></DisplayText><record><rec-number>1080</rec-number><foreign-keys><key app="EN" db-id="pt5wps9zupfdv5er0w9x0pz6aee2ds2a92ax" timestamp="1405431527">1080</key></foreign-keys><ref-type name="Journal Article">17</ref-type><contributors><authors><author>Giarelli, E.</author><author>Bernhardt, B.

A./author><author>Mack, R./author><author>Pyeritz, R.

E./author></authors></contributors><auth-address>(Giarelli) University of Pennsylvania, School of Nursing, Biobehavioral Research Center, 418 Curie Blvd., Philadelphia, PA 19104, United States&#xD;(Bernhardt) Department of Medicine, University of Pennsylvania, 418 Curie Blvd., Philadelphia, PA 19104, United States&#xD;(Mack) Biobehavioral Research Division, University of Pennsylvania, School of Nursing, 418 Curie Blvd., Philadelphia, PA 19104, United States&#xD;(Pyeritz) Division of Medical Genetics, University of Pennsylvania, School of Medicine, 418 Curie Blvd., Philadelphia, PA 19104, United States</auth-

address><titles><title>Adolescents&apos; transition to self-management of a chronic genetic disorder</title><secondary-title>Qualitative Health Research</secondary-

title></titles><periodical><full-title>Qualitative Health Research</full-

title></periodical><pages>441-

457</pages><volume>18</volume><number>4</number><dates><year>2008</year></dates><isbn

>1049-7323&#xD;1552-7557</isbn></urls></record></Cite></EndNote>}}]. They employed

strategies for ensuring that their child was aware of and had access to their own medical history and practiced asking questions for consultations. Parents talked about offering "tangible assistance" [{

ADDIN EN.CITE

<EndNote><Cite><Author>Hanna</Author><Year>2001</Year><RecNum>4523</RecNum><Suffix>`,

p.216</Suffix><DisplayText><style face="superscript">33,

p.216</style></DisplayText><record><rec-number>4523</rec-number><foreign-keys><key

app="EN" db-id="exwx9f9epzv52ezvipppa79z22d9pawfes"

timestamp="1452524284">4523</key></foreign-keys><ref-type name="Journal Article">17</ref-

type><contributors><authors><author>Hanna, K. M. </author><author>Guthrie, D.

</author></authors></contributors><titles><title>Parents' and adolescents' perceptions of helpful

and non-helpful support for adolescents' assumption of diabetes management

responsibility.</title><secondary-title>Issues in Comprehensive Pediatric Nursing</secondary-

title></titles><periodical><full-title>Issues in Comprehensive Pediatric Nursing</full-

title></periodical><pages>209-

223</pages><volume>24</volume><dates><year>2001</year></dates><urls></urls></record></Cit

e></EndNote>}} to their child in terms of filling prescriptions, making appointments and transporting

the child to clinic. This was presented as the young person taking responsibility for self-management

by instigating treatment adherence, but parents providing assistance where needed. Such a 'shared

care' approach, where parents and young people worked in partnership to manage the health

condition was described as a useful intermediary between parental and young person management.

#### 3.4.4 Service provision

Concerns were raised about changes to service provision across paediatric- and adult-centred healthcare. In contrast to the adult sector, children's services were viewed as providing care that was tailored to the child's "unique and complex" needs [{ ADDIN EN.CITE

<EndNote><Cite><Author>Davies</Author><Year>2011</Year><RecNum>6151</RecNum><Suffix>`,

p.35</Suffix><DisplayText><style face="superscript">34, p.35</style></DisplayText><record><rec-

number>6151</rec-number><foreign-keys><key app="EN" db-

id="pt5wps9zupfdv5er0w9x0pz6aee2ds2a92ax" timestamp="1429622894">6151</key></foreign-

keys><ref-type name="Journal Article">17</ref-type><contributors><authors><author>Davies,

H.</author><author>Rennick, J.</author><author>Majnemer, A.



</author></authors></contributors><titles><title>Transition from pediatric to adult health care for young adults with neurological disorders: Parental perspectives</title><secondary-title>Canadian Journal of Neuroscience Nursing</secondary-title></titles><periodical><full-title>Canadian Journal of Neuroscience Nursing</full-title></periodical><pages>32-39</pages><volume>33</volume><number>2</number><dates><year>2011</year></dates><urls></urls></record></Cite></EndNote>}} within a “warm, familiar, cosy and trusted” environment [{ ADDIN EN.CITE <EndNote><Cite><Author>van Staa</Author><Year>2011</Year><RecNum>249</RecNum><Suffix>`, p.826</Suffix><DisplayText><style face="superscript">35, p.826</style></DisplayText><record><rec-number>249</rec-number><foreign-keys><key app="EN" db-id="exwx9f9epzvv52ezrvippa79z22d9pawfes" timestamp="1397134593">249</key></foreign-keys><ref-type name="Journal Article">17</ref-type><contributors><authors><author>van Staa, A. L. </author><author>Jedeloo, S. </author><author>van Meeteren, J. </author><author>Latour, J. M. </author></authors></contributors><titles><title>Crossing the transition chasm: experiences and recommendations for improving transitional care of young adults, parents and providers</title><secondary-title>Child: care, health and development</secondary-title></titles><periodical><full-title>Child: care, health and development</full-title></periodical><pages>821–832</pages><volume>37</volume><number>6</number><dates><year>2011</year></dates><urls></urls></record></Cite></EndNote>}}. However, lack of preparation for transfer between services and a perceived lack of transitional care left parents experiencing a sense of “loss” [{ ADDIN EN.CITE <EndNote><Cite><Author>Young</Author><Year>2009</Year><RecNum>6152</RecNum><Suffix>`, p.351</Suffix><DisplayText><style face="superscript">36, p.351</style></DisplayText><record><rec-number>6152</rec-number><foreign-keys><key app="EN" db-id="pt5wps9zupfdv5er0w9x0pz6aee2ds2a92ax" timestamp="1429631265">6152</key></foreign-keys><ref-type name="Journal Article">17</ref-type><contributors><authors><author>Young, N. L. </author><author>Barden, W. S. </author><author>Mills, W. A. </author><author>Burke, T. A. </author><author>Law, M. </author><author>Boydell, K. </author></authors></contributors><titles><title>Transition to Adult-Oriented Health Care: Perspectives of Youth and Adults with Complex Physical Disabilities</title><secondary-title>Physical & Occupational Therapy in Pediatrics </secondary-title></titles><periodical><full-title>Physical & Occupational Therapy in Pediatrics</full-title></periodical><pages>345–361</pages><volume>29</volume><number>4</number><dates><year>2009</year></dates><urls></urls></record></Cite></EndNote>}} of support, resources and trusted relationships. This was regarded as a form of “abandonment and rejection” by paediatric professionals [{ ADDIN EN.CITE <EndNote><Cite><Author>Schultz</Author><Year>2013</Year><RecNum>4525</RecNum><Suffix>`, p.362</Suffix><DisplayText><style face="superscript">37, p.362</style></DisplayText><record><rec-number>4525</rec-number><foreign-keys><key app="EN" db-id="exwx9f9epzvv52ezrvippa79z22d9pawfes" timestamp="1452524827">4525</key></foreign-keys><ref-type name="Journal Article">17</ref-type><contributors><authors><author>Schultz, R. J. </author></authors></contributors><titles><title>Parental Experiences Transitioning Their Adolescent With Epilepsy and Cognitive Impairments to Adult Health Care</title><secondary-title>Journal of Paediatric Healthcare</secondary-title></titles><periodical><full-title>Journal of

Paediatric Healthcare

359-366

27

5

2013

The absence of adequate transitional care further left parents to act as their child's transition co-ordinator, assuming responsibility for communicating between services, arranging orientation visits and clinic appointments at new hospital sites and organising the transfer of clinical notes. Service changes impacted on parents in terms of them experiencing a discontinuity of information from lone consulting and a loss of "their own support systems" [

ADDIN EN.CITE

Hauser

1999

4524

38,

484

4524

EN

exwx9f9epzvv52ezrvippa79z22d9pawfes

1452524664

4524

Journal Article

17

Hauser, E. S.

Dorn, L.

Transitioning adolescents with sickle cell disease to adult-centred care

Pediatric nursing

Pediatric Nursing

479-488

25

5

1999

Suggestions for improvement included better collaboration between paediatric and adult sectors; joint visits; starting the process of transition earlier; increased information provision, transition preparation and support groups.

### 3.4.5 Young Person Condition Management

Parents described varying degrees of involvement in the management of their child's condition, with mothers describing themselves as highly involved in managing their child's LTC on a day-to-day basis, taking responsibility for ensuring treatment adherence and administration [

ADDIN EN.CITE

Williams

2007

240

10,

2138

240

EN

exwx9f9epzvv52ezrvippa79z22d9pawfes

1397039137

240

Journal Article

17

Williams, B.

Mukhopadhyay, S.

Dowell, J.

Coyle, J.

From child to adult: An exploration of shifting family roles and responsibilities in managing physiotherapy for cystic fibrosis

Social Science & Medicine

Social Science & Medicine

2135-2146

2007

In contrast, fathers were found to take a more laissez-fair approach, assuming responsibility for ensuring the health of all family members rather than concentrating solely on the child's condition [

ADDIN EN.CITE

Akre

2014

3

39,

767

3

EN

0evfxx22gv2057efdww5azwh5pxzxdw0ppr

1459770529

3

keys><ref-type name="Journal Article">17</ref-type><contributors><authors><author>Akre, Christina</author><author>Suris, Joan-Carles</author></authors></contributors><titles><title>From controlling to letting go: what are the psychosocial needs of parents of adolescents with a chronic illness?</title><secondary-title>Health Education Research</secondary-title></titles><pages>764-772</pages><volume>29</volume><number>5</number><dates><year>2014</year><pub-dates><date>October 1, 2014</date></pub-dates></dates><urls><related-urls><url>http://her.oxfordjournals.org/content/29/5/764.abstract</url></related-urls></urls><electronic-resource-num>10.1093/her/cyu040</electronic-resource-num></record></Cite></EndNote>]]. Many parents described conflicts arising from their protective parenting behaviours, for example, constant checking and questioning of their child's treatment adherence, lifestyle choices or engagement in potentially risky behaviours [{ ADDIN EN.CITE <EndNote><Cite><Author>Ivey</Author><Year>2009</Year><RecNum>243</RecNum><Suffix>', p.13</Suffix><DisplayText><style face="superscript">40, p. 13</style></DisplayText><record><rec-number>243</rec-number><foreign-keys><key app="EN" db-id="exwx9f9epzv52ezrvippa79z22d9pawfes" timestamp="1397127832">243</key></foreign-keys><ref-type name="Journal Article">17</ref-type><contributors><authors><author>Ivey, J. B.</author><author>Wright, A.</author><author>Dashiff, C. J.</author></authors></contributors><titles><title>Finding the Balance: Adolescents With Type 1 Diabetes and Their Parents</title><secondary-title>Journal of Pediatric Health Care</secondary-title></titles><periodical><full-title>Journal of Pediatric Health Care</full-title></periodical><pages>10-18</pages><volume>23</volume><dates><year>2009</year></dates><urls></urls></record></Cite></EndNote>]].

### 3.5 Understanding how parents experience their care-giving role in relation to their own well-being

#### 3.5.1 Parents' experiences of their child's healthcare transition

Parents' experiences of their child's healthcare transition were characterised by feelings of "stress" [{ ADDIN EN.CITE <EndNote><Cite><Author>Davies</Author><Year>2011</Year><RecNum>6151</RecNum><Suffix>', p.36</Suffix><DisplayText><style face="superscript">34, p.36</style></DisplayText><record><rec-number>6151</rec-number><foreign-keys><key app="EN" db-id="pt5wps9zupfdv5er0w9x0pz6aee2ds2a92ax" timestamp="1429622894">6151</key></foreign-keys><ref-type name="Journal Article">17</ref-type><contributors><authors><author>Davies, H.</author><author>Rennick, J.</author><author>Majnemer, A.</author></authors></contributors><titles><title>Transition from pediatric to adult health care for young adults with neurological disorders: Parental perspectives</title><secondary-title>Canadian Journal of Neuroscience Nursing</secondary-title></titles><periodical><full-title>Canadian Journal of Neuroscience Nursing</full-title></periodical><pages>32-39</pages><volume>33</volume><number>2</number><dates><year>2011</year></dates><urls></urls></record></Cite></EndNote>]], "turmoil" [{ ADDIN EN.CITE <EndNote><Cite><Author>Schultz</Author><Year>2013</Year><RecNum>4525</RecNum><Suffix>', p.361</Suffix><DisplayText><style face="superscript">37,

p.361</style></DisplayText><record><rec-number>4525</rec-number><foreign-keys><key app="EN" db-id="exwx9f9epzv52ezrvippa79z22d9pawfes" timestamp="1452524827">4525</key></foreign-keys><ref-type name="Journal Article">17</ref-type><contributors><authors><author>Schultz, R. J. </author></authors></contributors><titles><title>Parental Experiences Transitioning Their Adolescent With Epilepsy and Cognitive Impairments to Adult Health Care</title><secondary-title>Journal of Paediatric Healthcare</secondary-title></titles><periodical><full-title>Journal of Paediatric Healthcare</full-title></periodical><pages>359-366</pages><volume>27</volume><number>5</number><dates><year>2013</year></dates><urls></urls></record></Cite></EndNote>}} and "fear" [{ ADDIN EN.CITE <EndNote><Cite><Author>Schultz</Author><Year>2013</Year><RecNum>4525</RecNum><Suffix>` , p.362</Suffix><DisplayText><style face="superscript">37, p.362</style></DisplayText><record><rec-number>4525</rec-number><foreign-keys><key app="EN" db-id="exwx9f9epzv52ezrvippa79z22d9pawfes" timestamp="1452524827">4525</key></foreign-keys><ref-type name="Journal Article">17</ref-type><contributors><authors><author>Schultz, R. J. </author></authors></contributors><titles><title>Parental Experiences Transitioning Their Adolescent With Epilepsy and Cognitive Impairments to Adult Health Care</title><secondary-title>Journal of Paediatric Healthcare</secondary-title></titles><periodical><full-title>Journal of Paediatric Healthcare</full-title></periodical><pages>359-366</pages><volume>27</volume><number>5</number><dates><year>2013</year></dates><urls></urls></record></Cite></EndNote>}}. Stress and turmoil related to the families' detachment from paediatric services and "uncertainty" [{ ADDIN EN.CITE <EndNote><Cite><Author>Kirk</Author><Year>2014</Year><RecNum>4526</RecNum><Suffix>` , p.345</Suffix><DisplayText><style face="superscript">41, p.345</style></DisplayText><record><rec-number>4526</rec-number><foreign-keys><key app="EN" db-id="exwx9f9epzv52ezrvippa79z22d9pawfes" timestamp="1452524951">4526</key></foreign-keys><ref-type name="Journal Article">17</ref-type><contributors><authors><author>Kirk, S. </author><author>Fraser, C. </author></authors></contributors><titles><title>Hospice support and the transition to adult services and adulthood for young people with life-limiting conditions and their families: A qualitative study</title><secondary-title>Palliative Medicine</secondary-title></titles><periodical><full-title>Palliative Medicine</full-title></periodical><pages>342-353</pages><volume>28</volume><number>4</number><dates><year>2014</year></dates><urls></urls></record></Cite></EndNote>}} regarding the move to adult care. A prominent source of anxiety was the tension between how much control parents should maintain over their child's condition/treatment and "how much responsibility" [{ ADDIN EN.CITE <EndNote><Cite><Author>Buford</Author><Year>2004</Year><RecNum>238</RecNum><Suffix>` , p.4</Suffix><DisplayText><style face="superscript">30, p.4</style></DisplayText><record><rec-number>238</rec-number><foreign-keys><key app="EN" db-id="pt5wps9zupfdv5er0w9x0pz6aee2ds2a92ax" timestamp="1405430531">238</key></foreign-keys><ref-type name="Journal Article">17</ref-type><contributors><authors><author>Buford, T. A.</author></authors></contributors><titles><title>Transfer of asthma management responsibility from parents to their school-age children</title><secondary-title>Journal of Pediatric Nursing</secondary-title></titles><periodical><full-title>Journal of Pediatric Nursing</full-

title</periodical><pages>3-13</pages><volume>19</volume><number>1</number><dates><year>2004</year></dates><isbn>08825963</isbn><urls></urls></record></Cite></EndNote>}} they should handover to the young person. Parental reluctance to relinquish control was linked to their fear of “long-term health complications” [{ ADDIN EN.CITE <EndNote><Cite><Author>Mellin</Author><Year>2002</Year><RecNum>4527</RecNum><Suffix>`, p.224</Suffix><DisplayText><style face="superscript">42, p.224</style></DisplayText><record><rec-number>4527</rec-number><foreign-keys><key app="EN" db-id="exwx9f9epzv52ezrvippa79z22d9pawfes" timestamp="1452525780">4527</key></foreign-keys><ref-type name="Journal Article">17</ref-type><contributors><authors><author>Mellin, A. E. </author><author>Neumark-Sztainer, D.</author><author>Patterson, J. M. </author></authors></contributors><titles><title>Parenting Adolescent Girls with Type 1 Diabetes: Parents’ Perspectives</title><secondary-title>Journal of Paediatric Psychology</secondary-title></titles><periodical><full-title>Journal of Paediatric Psychology</full-title></periodical><pages>221-230</pages><volume>29</volume><number>3</number><dates><year>2002</year></dates><urls></urls></record></Cite></EndNote>}} resulting from their child’s engagement in risky behaviours including treatment non-adherence. “Letting go” [{ ADDIN EN.CITE <EndNote><Cite><Author>Akre</Author><Year>2014</Year><RecNum>6141</RecNum><Suffix>`, p.768</Suffix><DisplayText><style face="superscript">39, p.768</style></DisplayText><record><rec-number>6141</rec-number><foreign-keys><key app="EN" db-id="pt5wps9zupfdv5er0w9x0pz6aee2ds2a92ax" timestamp="1429548542">6141</key></foreign-keys><ref-type name="Journal Article">17</ref-type><contributors><authors><author>Akre, Christina</author><author>Suris, Joan-Carles</author></authors></contributors><titles><title>From controlling to letting go: what are the psychosocial needs of parents of adolescents with a chronic illness?</title><secondary-title>Health Education Research</secondary-title></titles><periodical><full-title>Health Education Research</full-title></periodical><pages>764-772</pages><volume>29</volume><number>5</number><dates><year>2014</year><pub-dates><date>October 1, 2014</date></pub-dates></dates><urls><related-urls><url>http://her.oxfordjournals.org/content/29/5/764.abstract</url></related-urls></urls><electronic-resource-num>10.1093/her/cyu040</electronic-resource-num></record></Cite></EndNote>}} of control over their child’s condition and treatment was found to be a “difficult process” [{ ADDIN EN.CITE <EndNote><Cite><Author>Allen</Author><Year>2011</Year><RecNum>4412</RecNum><Suffix>`, p.999</Suffix><DisplayText><style face="superscript">28, p.999</style></DisplayText><record><rec-number>4412</rec-number><foreign-keys><key app="EN" db-id="exwx9f9epzv52ezrvippa79z22d9pawfes" timestamp="1408372714">4412</key></foreign-keys><ref-type name="Journal Article">17</ref-type><contributors><authors><author>Allen, D. </author><author>Channon, S, </author><author>Lowes, L. </author><author>Atwell, C. </author><author>Lane, C. </author></authors></contributors><titles><title>Behind the scenes: the changing roles of parents in the transition from child to adult diabetes service</title><secondary-title>Diabetic Medicine</secondary-title></titles><periodical><full-title>Diabetic Medicine</full-title></periodical><pages>994–

1000</pages><volume>28</volume><dates><year>2011</year></dates><urls></urls></record></Cite></EndNote>}} for parents, while maintaining control helped to manage their anxiety. However, this “need to stay involved in the child’s health care” [{ ADDIN EN.CITE <EndNote><Cite><Author>Giarelli</Author><Year>2008</Year><RecNum>4528</RecNum><Suffix>`, p.330</Suffix><DisplayText><style face="superscript">43, p.330</style></DisplayText><record><rec-number>4528</rec-number><foreign-keys><key app="EN" db-id="exwx9f9epzv52ezrvippa79z22d9pawfes" timestamp="1452526041">4528</key></foreign-keys><ref-type name="Journal Article">17</ref-type><contributors><authors><author>Giarelli, E.</author><author>Bernhardt, B. A.</author><author>Pyeritz, R. E.</author></authors></contributors><titles><title>Attitudes antecedent to transition to self-management of a chronic genetic disorder</title><secondary-title>Clinical Genetics</secondary-title></titles><periodical><full-title>Clinical Genetics</full-title></periodical><pages>325-337</pages><volume>74</volume><number>4</number><dates><year>2008</year></dates><urls></urls></record></Cite></EndNote>}} delayed the onset of young person autonomy. Enlisting a network of “others outside the family” (e.g. friends, professionals at school/college) [{ ADDIN EN.CITE <EndNote><Cite><Author>Mellin</Author><Year>2002</Year><RecNum>4527</RecNum><Suffix>`, p.226</Suffix><DisplayText><style face="superscript">42, p.226</style></DisplayText><record><rec-number>4527</rec-number><foreign-keys><key app="EN" db-id="exwx9f9epzv52ezrvippa79z22d9pawfes" timestamp="1452525780">4527</key></foreign-keys><ref-type name="Journal Article">17</ref-type><contributors><authors><author>Mellin, A. E. </author><author>Neumark-Sztainer, D.</author><author>Patterson, J. M. </author></authors></contributors><titles><title>Parenting Adolescent Girls with Type 1 Diabetes: Parents’ Perspectives</title><secondary-title>Journal of Paediatric Psychology</secondary-title></titles><periodical><full-title>Journal of Paediatric Psychology</full-title></periodical><pages>221-230</pages><volume>29</volume><number>3</number><dates><year>2002</year></dates><urls></urls></record></Cite></EndNote>}}, who would help the young person adjust to their increasing independence and provide self-management support in the absence of parents also served to manage parental worry.

### 3.5.2 Parental transition

Included studies indicated that parents too were required to go through a process of transition, from parenting a child to parenting a young adult with a LTC. This transition presented “developmental challenges” [{ ADDIN EN.CITE <EndNote><Cite><Author>Allen</Author><Year>2011</Year><RecNum>4412</RecNum><Suffix>`, p.999</Suffix><DisplayText><style face="superscript">28, p.999</style></DisplayText><record><rec-number>4412</rec-number><foreign-keys><key app="EN" db-id="exwx9f9epzv52ezrvippa79z22d9pawfes" timestamp="1408372714">4412</key></foreign-keys><ref-type name="Journal Article">17</ref-type><contributors><authors><author>Allen, D. </author><author>Channon, S,</author><author>Lowes, L. </author><author>Atwell, C. </author><author>Lane, C.</author></authors></contributors><titles><title>Behind the scenes: the changing roles of parents in the transition from child to adult diabetes service</title><secondary-title>Diabetic

Medicine

Diabetic Medicine

994–1000

28

2011

for parents themselves, demanding changes to their behaviour and adjustment to their role. An example was substituting “watching”

30, p.9

238

Transfer of asthma management responsibility from parents to their school-age children

Journal of Pediatric Nursing

3–13

19

1

2004

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a young person administer treatment with “passive supervising”

10, p.2139

240

From child to adult: An exploration of shifting family roles and responsibilities in managing physiotherapy for cystic fibrosis

Social Science & Medicine

2135–2146

2007

In particular, parents described having to revise “their definition for successful [condition] management”

42, p.226

4527

Parenting Adolescent Girls with Type 1 Diabetes: Parents’ Perspectives

Journal of Paediatric Psychology

221–230

29

3

2002

in line with what their child could achieve. In several studies parents expressed “ambiguity and uncertainty about what the new arrangements for care signified about their changed role”

<EndNote><Cite><Author>Allen</Author><Year>2011</Year><RecNum>4412</RecNum><Suffix>`,  
p.997</Suffix><DisplayText><style face="superscript">28,  
p.997</style></DisplayText><record><rec-number>4412</rec-number><foreign-keys><key  
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timestamp="1408372714">4412</key></foreign-keys><ref-type name="Journal Article">17</ref-  
type><contributors><authors><author>Allen, D. </author><author>Channon, S,  
</author><author>Lowes, L. </author><author>Atwell, C. </author><author>Lane, C.  
</author></authors></contributors><titles><title>Behind the scenes: the changing roles of parents  
in the transition from child to adult diabetes service</title><secondary-title>Diabetic  
Medicine</secondary-title></titles><periodical><full-title>Diabetic Medicine</full-  
title></periodical><pages>994–  
1000</pages><volume>28</volume><dates><year>2011</year></dates><urls></urls></record></C  
ite></EndNote>}}; struggling to reconcile relinquishing control with providing support and guidance.  
Frequently this meant that parental support was not withdrawn completely, but that their  
previously held “managerial role” gave way to a new “consultant role” [{ ADDIN EN.CITE  
<EndNote><Cite><Author>Sparacino</Author><Year>1997</Year><RecNum>4529</RecNum><Suffi  
x>`, p.190</Suffix><DisplayText><style face="superscript">44,  
p.190</style></DisplayText><record><rec-number>4529</rec-number><foreign-keys><key  
app="EN" db-id="exwx9f9epzv52ezrvippa79z22d9pawfes"  
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type><contributors><authors><author>Sparacino, P. S. A.</author><author>Tong, E.  
M.</author><author>Messias, D. K. H.</author><author>Foote, D.</author><author>Chesla, C. A.  
</author><author>Gilliss, C. L. </author></authors></contributors><titles><title>The dilemmas of  
parents of adolescents and young adults with congenital heart disease</title><secondary-title>Heart  
& Lung</secondary-title></titles><periodical><full-title>Heart & Lung</full-  
title></periodical><pages>187-  
195</pages><volume>26</volume><number>3</number><dates><year>1997</year></dates><urls  
></urls></record></Cite></EndNote>}}. Most challenging was the role of “passive initiator” where  
parents initiated but had “no direct involvement or knowledge” [{ ADDIN EN.CITE  
<EndNote><Cite><Author>Williams</Author><Year>2007</Year><RecNum>240</RecNum><Suffix>`,  
p.2140</Suffix><DisplayText><style face="superscript">10,  
p.2140</style></DisplayText><record><rec-number>240</rec-number><foreign-keys><key  
app="EN" db-id="exwx9f9epzv52ezrvippa79z22d9pawfes"  
timestamp="1397039137">240</key></foreign-keys><ref-type name="Journal Article">17</ref-  
type><contributors><authors><author>Williams, B.</author><author>Mukhopadhyay, S.  
</author><author>Dowell, J. </author><author>Coyle, J.  
</author></authors></contributors><titles><title>From child to adult: An exploration of shifting  
family roles and responsibilities in managing physiotherapy for cystic fibrosis</title><secondary-  
title>Social Science & Medicine</secondary-title></titles><periodical><full-title>Social Science  
& Medicine</full-title></periodical><pages>2135–  
2146</pages><dates><year>2007</year></dates><urls></urls></record></Cite></EndNote>}} of  
the child’s condition management behaviours beyond reminding them.

### 3.5.3 Impact of LTC on family



Parents described how their child's LTC impacted on their family, including the impact of the condition on siblings, on parents' other roles, relationships and responsibilities and on the child's capacity to live a 'normal' life. Parents felt it was their duty to maintain "a positive attitude and outlook" for their child [{ ADDIN EN.CITE

<EndNote><Cite><Author>Mellin</Author><Year>2002</Year><RecNum>4527</RecNum><Suffix>', p.226</Suffix><DisplayText><style face="superscript">42, p.226</style></DisplayText><record><rec-number>4527</rec-number><foreign-keys><key app="EN" db-id="exwx9f9epzv52ezrvippa79z22d9pawfes" timestamp="1452525780">4527</key></foreign-keys><ref-type name="Journal Article">17</ref-type><contributors><authors><author>Mellin, A. E. </author><author>Neumark-Sztainer, D.</author><author>Patterson, J. M. </author></authors></contributors><titles><title>Parenting Adolescent Girls with Type 1 Diabetes: Parents' Perspectives</title><secondary-title>Journal of Paediatric Psychology</secondary-title></titles><periodical><full-title>Journal of Paediatric Psychology</full-title></periodical><pages>221-

230</pages><volume>29</volume><number>3</number><dates><year>2002</year></dates><urls></urls></record></Cite></EndNote>}], redirecting focus away from the young person's limitations toward "possibilities of the future" [{ ADDIN EN.CITE

<EndNote><Cite><Author>Giarelli</Author><Year>2008</Year><RecNum>1080</RecNum><Suffix>', p.449</Suffix><DisplayText><style face="superscript">32, p.449</style></DisplayText><record><rec-number>1080</rec-number><foreign-keys><key app="EN" db-id="pt5wps9zupfdv5er0w9x0pz6aee2ds2a92ax" timestamp="1405431527">1080</key></foreign-keys><ref-type name="Journal Article">17</ref-type><contributors><authors><author>Giarelli, E.</author><author>Bernhardt, B. A.</author><author>Mack, R.</author><author>Pyeritz, R. E.</author></authors></contributors><auth-address>(Giarelli) University of Pennsylvania, School of Nursing, Biobehavioral Research Center, 418 Curie Blvd., Philadelphia, PA 19104, United States&#xD;(Bernhardt) Department of Medicine, University of Pennsylvania, 418 Curie Blvd., Philadelphia, PA 19104, United States&#xD;(Mack) Biobehavioral Research Division, University of Pennsylvania, School of Nursing, 418 Curie Blvd., Philadelphia, PA 19104, United States&#xD;(Pyeritz) Division of Medical Genetics, University of Pennsylvania, School of Medicine, 418 Curie Blvd., Philadelphia, PA 19104, United States</auth-

address><titles><title>Adolescents' transition to self-management of a chronic genetic disorder</title><secondary-title>Qualitative Health Research</secondary-title></titles><periodical><full-title>Qualitative Health Research</full-title></periodical><pages>441-457</pages><volume>18</volume><number>4</number><dates><year>2008</year></dates><isbn>1049-7323&#xD;1552-7557</isbn><urls></urls></record></Cite></EndNote>}. Parents described their desire to maintain a sense of "normalcy" for their child [{ ADDIN EN.CITE

<EndNote><Cite><Author>Mellin</Author><Year>2002</Year><RecNum>4527</RecNum><Suffix>', p.226</Suffix><DisplayText><style face="superscript">42, p.226</style></DisplayText><record><rec-number>4527</rec-number><foreign-keys><key app="EN" db-id="exwx9f9epzv52ezrvippa79z22d9pawfes" timestamp="1452525780">4527</key></foreign-keys><ref-type name="Journal Article">17</ref-type><contributors><authors><author>Mellin, A. E. </author><author>Neumark-Sztainer, D.</author><author>Patterson, J. M. </author></authors></contributors><titles><title>Parenting

Adolescent Girls with Type 1 Diabetes: Parents' Perspectives

Journal of Paediatric Psychology

Journal of Paediatric Psychology

221-230

29

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2002

This was achieved through treating the LTC as a "normal part of life" [ { ADDIN EN.CITE <EndNote><Cite><Author>Ivey</Author><Year>2009</Year><RecNum>6146</RecNum><Suffix>', p.12</Suffix><DisplayText><style face="superscript">45, p.12</style></DisplayText><record><rec-number>6146</rec-number><foreign-keys><key app="EN" db-id="pt5wps9zupfdv5er0w9x0pz6aee2ds2a92ax" timestamp="1429610825">6146</key></foreign-keys><ref-type name="Journal Article">17</ref-type><contributors><authors><author>Ivey, J. B.</author><author>Wright, A. </author><author>Dashiff, C. J.</author></authors></contributors><titles><title>Finding the Balance: Adolescents With Type 1 Diabetes and Their Parents</title><secondary-title>J Pediatr Health Care</secondary-title></titles><periodical><full-title>J Pediatr Health Care</full-title></periodical><pages>10-18</pages><volume>23</volume><dates><year>2009</year></dates><urls></urls></record></Cite></EndNote>}} and ensuring that the child lived as "normal" [ { ADDIN EN.CITE <EndNote><Cite><Author>Sparacino</Author><Year>1997</Year><RecNum>4529</RecNum><Suffix>', p.190</Suffix><DisplayText><style face="superscript">44, p.190</style></DisplayText><record><rec-number>4529</rec-number><foreign-keys><key app="EN" db-id="exwx9f9epzv52ezrvippa79z22d9pawfes" timestamp="1452526413">4529</key></foreign-keys><ref-type name="Journal Article">17</ref-type><contributors><authors><author>Sparacino, P. S. A.</author><author>Tong, E. M.</author><author>Messias, D. K. H.</author><author>Foote, D.</author><author>Chesla, C. A.</author><author>Gilliss, C. L. </author></authors></contributors><titles><title>The dilemmas of parents of adolescents and young adults with congenital heart disease</title><secondary-title>Heart & Lung</secondary-title></titles><periodical><full-title>Heart & Lung</full-title></periodical><pages>187-195</pages><volume>26</volume><number>3</number><dates><year>1997</year></dates><urls></urls></record></Cite></EndNote>}} a life as possible, despite their LTC. However, also expressed was a sense of "burden" [ { ADDIN EN.CITE <EndNote><Cite><Author>Hartman</Author><Year>2000</Year><RecNum>4530</RecNum><Suffix>', p.53</Suffix><DisplayText><style face="superscript">46, p.53</style></DisplayText><record><rec-number>4530</rec-number><foreign-keys><key app="EN" db-id="exwx9f9epzv52ezrvippa79z22d9pawfes" timestamp="1452527174">4530</key></foreign-keys><ref-type name="Journal Article">17</ref-type><contributors><authors><author>Hartman, A.</author><author>DePoy, E.</author><author>Francis, C.</author><author>Gilmer, D.</author></authors></contributors><titles><title>Adolescents with special health care needs in transition: three life histories</title><secondary-title>Social Work in Health Care</secondary-title></titles><periodical><full-title>Social Work in Health Care</full-title></periodical><pages>43-57</pages><volume>31</volume><number>4</number><dates><year>2000</year></dates><urls></urls></record></Cite></EndNote>}} and burnout from parenting a child with a chronic illness, particularly those with life-limiting conditions.

#### 4. Discussion and Conclusion

#### 4.1 Discussion

This review thematically synthesised 32 papers from six countries reporting how parents understand and experience their role as their child with a LTC transitions into adulthood and adult healthcare services. Developing understanding of the parent perspective is essential for ensuring the provision of effective transitional healthcare. Although studies were diverse in terms of LTCs, they were comparable, enabling the development of overarching themes.

Findings revealed that parents generally view their child's progression towards self-care as a positive and incremental process which they seek to facilitate through up-skilling them in self-management practices. Parent perceptions of their child's readiness, wellness, competence and LTC impacted on child healthcare autonomy. A lack of transitional care, perceived differences between paediatric and adult services, and a loss of relationships, resources and support for parents and young people served as barriers to effective healthcare transition. Parents' experiences of their child's healthcare transition were characterised by ambiguity and uncertainty, leading to feelings of anxiety and distress. A strong source of anxiety related to fear of poor health outcomes from relinquishing control of the condition to the young person. In parallel with their adolescent child, parents were required to go through their own process of transition. This involved supporting the child's growing independence and adapting to a new role. Parents required support from healthcare providers to prepare for and manage their child's healthcare transition.

The core finding that parents have difficulties relinquishing control of their child's LTC for fear of poor health outcomes supports previous research on healthcare transition from the perspectives of young people and professionals [14, 15, 16, 17, 18, 19, 20, 21, 22, 23, 24, 25, 26, 27, 28, 29, 30, 31, 32, 33, 34, 35, 36, 37, 38, 39, 40, 41, 42, 43, 44, 45, 46, 47, 48, 49]. It also aligns with research on emerging adulthood in a non-clinical population [49]. **In this review**, parental reluctance to relinquish control was related to perceived risk of shifting allocation of treatment responsibility to young people, and to inadequate professional co-ordination of the child's transfer across services [14, 15, 16, 17, 18, 19, 20, 21, 22, 23, 24, 25, 26, 27, 28, 29, 30, 31, 32, 33, 34, 35, 36, 37, 38, 39, 40, 41, 42, 43, 44, 45, 46, 47, 48, 49].

**31** [14, 15, 16, 17, 18, 19, 20, 21, 22, 23, 24, 25, 26, 27, 28, 29, 30, 31, 32, 33, 34, 35, 36, 37, 38, 39, 40, 41, 42, 43, 44, 45, 46, 47, 48, 49]. While protective parenting practices served to promote child safety, they could also lead to reduced autonomy in early adulthood [14, 15, 16, 17, 18, 19, 20, 21, 22, 23, 24, 25, 26, 27, 28, 29, 30, 31, 32, 33, 34, 35, 36, 37, 38, 39, 40, 41, 42, 43, 44, 45, 46, 47, 48, 49].

**15 50** [14, 15, 16, 17, 18, 19, 20, 21, 22, 23, 24, 25, 26, 27, 28, 29, 30, 31, 32, 33, 34, 35, 36, 37, 38, 39, 40, 41, 42, 43, 44, 45, 46, 47, 48, 49].

**228** [14, 15, 16, 17, 18, 19, 20, 21, 22, 23, 24, 25, 26, 27, 28, 29, 30, 31, 32, 33, 34, 35, 36, 37, 38, 39, 40, 41, 42, 43, 44, 45, 46, 47, 48, 49].

</author><author>Uhrenfeldt, L. </author><author>Aagaard, H. </author><author>Ludvigsen, M. S.  
</author></authors></contributors><titles><title>Adolescents' and young adults' transition  
experiences when transferring from paediatric to adult care: A qualitative  
metasynthesis</title><secondary-title>International Journal of Nursing Studies </secondary-  
title></titles><periodical><full-title>International Journal of Nursing Studies</full-  
title></periodical><pages>123–  
135</pages><volume>51</volume><dates><year>2014</year></dates><urls></urls></record></Cite  
e><Cite><Author>Seiffge-  
Krenke</Author><Year>2006</Year><RecNum>4533</RecNum><record><rec-number>4533</rec-  
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relationships and psychological health as predictors of different leaving home  
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876</pages><volume>42</volume><dates><year>2006</year></dates><urls></urls></record></Cite  
e></EndNote>}} stemming from increased parental attachment behaviour [{ ADDIN EN.CITE  
<EndNote><Cite><Author>Dashiff</Author><Year>2008</Year><RecNum>4543</RecNum><Display  
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D.</author><author>Abdullatif, H.</author><author>Wallander,  
J.</author></authors></contributors><titles><title>Parenting, autonomy and self-care of  
adolescents with Type 1 diabetes</title><secondary-title>Child: Care, Health & ;  
Development</secondary-title></titles><periodical><full-title>Child: Care, Health & ;  
Development</full-title></periodical><pages>79-  
88</pages><volume>35</volume><number>1</number><dates><year>2008</year></dates><urls>  
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adult responsibilities [{ ADDIN EN.CITE  
<EndNote><Cite><Author>Arnett</Author><Year>2000</Year><RecNum>4534</RecNum><DisplayT  
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</author></authors></contributors><titles><title>Emerging adulthood: A Theory of Development  
From the Late Teens Through the Twenties</title><secondary-title>American  
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title></periodical><pages>469-  
480</pages><volume>55</volume><number>5</number><dates><year>2000</year></dates><urls>  
></urls></record></Cite></EndNote>}}. Young people have also expressed frustration at the over-  
involvement of parents post healthcare transition [{ ADDIN EN.CITE  
<EndNote><Cite><Author>Iles</Author><Year>2010</Year><RecNum>4532</RecNum><DisplayTex

$53\ 54$

<record><rec-number>4532</rec-number><foreign-keys><key app="EN" db-id="exwx9f9epzv52ezrvippa79z22d9pawfes" timestamp="1452529616">4532</key></foreign-keys><ref-type name="Journal Article">17</ref-type><contributors><authors><author>Iles, N. </author><author>Lowton, K. </author></authors></contributors><titles><title>What is the perceived nature of parental care and support for young people with cystic fibrosis as they enter adult health services?</title><secondary-title>Health and Social Care in the Community (2010) 18(1), 21–29</secondary-title></titles><periodical><full-title>Health and Social Care in the Community (2010) 18(1), 21–29</full-title></periodical><pages>21–29</pages><volume>18</volume><number>1</number><dates><year>2010</year></dates><urls></urls></record></Cite><Cite><Author>Lambert</Author><Year>2014</Year><RecNum>4441</RecNum><record><rec-number>4441</rec-number><foreign-keys><key app="EN" db-id="exwx9f9epzv52ezrvippa79z22d9pawfes" timestamp="1422878018">4441</key></foreign-keys><ref-type name="Journal Article">17</ref-type><contributors><authors><author>Lambert, V.</author><author>Keogh, D. </author></authors></contributors><titles><title>Striving to Live a Normal Life: A Review of Children and Young People’s Experience of Feeling Different when Living with a Long Term Condition</title><secondary-title>Journal of Pediatric Nursing</secondary-title></titles><periodical><full-title>Journal of Pediatric Nursing</full-title></periodical><dates><year>2014</year></dates><urls><related-urls><url><http://dx.doi.org/10.1016/j.pedn.2014.09.016></url></related-urls></urls></record></Cite></EndNote>}}. Parents therefore appear to be more concerned than their children about the adolescent’s ability to be autonomous [{ ADDIN EN.CITE <EndNote><Cite><Author>van Staa</Author><Year>2011</Year><RecNum>249</RecNum><DisplayText><style face="superscript">35 55</style></DisplayText><record><rec-number>249</rec-number><foreign-keys><key app="EN" db-id="exwx9f9epzv52ezrvippa79z22d9pawfes" timestamp="1397134593">249</key></foreign-keys><ref-type name="Journal Article">17</ref-type><contributors><authors><author>van Staa, A. L. </author><author>Jedloo, S. </author><author>van Meeteren, J. </author><author>Latour, J. M. </author></authors></contributors><titles><title>Crossing the transition chasm: experiences and recommendations for improving transitional care of young adults, parents and providers</title><secondary-title>Child: care, health and development</secondary-title></titles><periodical><full-title>Child: care, health and development</full-title></periodical><pages>821–832</pages><volume>37</volume><number>6</number><dates><year>2011</year></dates><urls></urls></record></Cite><Cite><Author>Geerts</Author><Year>2008</Year><RecNum>4536</RecNum><record><rec-number>4536</rec-number><foreign-keys><key app="EN" db-id="exwx9f9epzv52ezrvippa79z22d9pawfes" timestamp="1452690005">4536</key></foreign-keys><ref-type name="Journal Article">17</ref-type><contributors><authors><author>Geerts, E.</author><author>van de Wiel, H.</author><author>Tamminga, R.</author></authors></contributors><titles><title>A pilot study on the effects of the transition of paediatric to adult health care in patients with haemophilia and in their parents: patient and parent worries, parental illness-related distress and health-related Quality of Life</title><secondary-title>Haemophilia </secondary-title></titles><periodical><full-title>Haemophilia</full-title></periodical><pages>1007–

1013

[{ ADDIN EN.CITE  
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Healthcare professionals are ideally placed to work with parents to facilitate their and their child's growth and change.

Four domains of perceived parental support have been identified by young people and professionals throughout transfer to adult services. These include parents providing practical support, acting as 'trouble-shooters' in times of health-related crisis, working in partnership with young people to manage their condition and providing emotional protection [ { ADDIN EN.CITE  
<EndNote><Cite><Author>Iles</Author><Year>2010</Year><RecNum>4532</RecNum><DisplayText><style face="superscript">53</style></DisplayText><record><rec-number>4532</rec-number><foreign-keys><key app="EN" db-id="exwx9f9epzvv52ezrvippa79z22d9pawfes" timestamp="1452529616">4532</key></foreign-keys><ref-type name="Journal Article">17</ref-type><contributors><authors><author>Iles, N.</author><author>Lowton, K.</author></authors></contributors><titles><title>What is the perceived nature of parental care and support for young people with cystic fibrosis as they enter adult health services?</title><secondary-title>Health and Social Care in the Community (2010) 18(1), 21–29</secondary-title></titles><periodical><full-title>Health and Social Care in the Community (2010) 18(1), 21–29</full-title></periodical><pages>21–29</pages><volume>18</volume><number>1</number><dates><year>2010</year></dates><urls></urls></record></Cite></EndNote>]].

Our findings support the need for parents to adjust their role to embrace that of 'partner'; sharing healthcare management with their child in a state of interdependence, as a bridge to full independence [ { ADDIN EN.CITE  
<EndNote><Cite><Author>Kieckhefer</Author><Year>2009</Year><RecNum>4537</RecNum><DisplayText><style face="superscript">57</style></DisplayText><record><rec-number>4537</rec-number><foreign-keys><key app="EN" db-id="exwx9f9epzvv52ezrvippa79z22d9pawfes" timestamp="1452691118">4537</key></foreign-keys><ref-type name="Journal Article">17</ref-type><contributors><authors><author>Kieckhefer, G. M.</author><author>Trahms, C. M.</author><author>Churchill, S. S.</author><author>Simpson, J. N.</author></authors></contributors><titles><title>Measuring parent-child shared management of chronic illness</title><secondary-title>Pediatric Nursing</secondary-title></titles><periodical><full-title>Pediatric Nursing</full-title></periodical><pages>101–8</pages><volume>35</volume><number>2</number><dates><year>2009</year></dates><urls></urls></record></Cite></EndNote>]].

/urls></record></Cite></EndNote>]]. Shared care might include parents ‘prompting’ young people to administer treatment, fulfilling prescriptions and up-skilling them in self-care activities. This role is similar to that of a ‘lay carer’ as described by parents of adults with LTCs [{ ADDIN EN.CITE <EndNote><Cite><Author>Lowton</Author><Year>2002</Year><RecNum>232</RecNum><DisplayText><style face="superscript">58</style></DisplayText><record><rec-number>232</rec-number><foreign-keys><key app="EN" db-id="exwx9f9epzvv52ezrvippa79z22d9pawfes" timestamp="1397038250">232</key></foreign-keys><ref-type name="Journal Article">17</ref-type><contributors><authors><author>Lowton, K. </author></authors></contributors><titles><title>Parents and partners: lay carers’ perceptions of their role in the treatment and care of adults with cystic fibrosis</title><secondary-title>Journal of Advanced Nursing</secondary-title></titles><periodical><full-title>Journal of Advanced Nursing</full-title></periodical><pages>174–181</pages><volume>39</volume><number>2</number><dates><year>2002</year></dates><urls></urls></record></Cite></EndNote>]].

While parents are responsible for adapting their role to support their child during transition, healthcare providers are responsible for providing transitional care that addresses the needs of both parents and young people. Working in partnership with parents, as well as young people, will likely lead to a smoother and more effective transition for all. However, despite acknowledgement of the need for parent-targeted transition support [{ ADDIN EN.CITE { ADDIN EN.CITE.DATA }}] Allen et al [{ ADDIN EN.CITE <EndNote><Cite ExcludeAuth="1"><Author>Allen</Author><Year>2011</Year><RecNum>4412</RecNum><DisplayText><style face="superscript">28</style></DisplayText><record><rec-number>4412</rec-number><foreign-keys><key app="EN" db-id="exwx9f9epzvv52ezrvippa79z22d9pawfes" timestamp="1408372714">4412</key></foreign-keys><ref-type name="Journal Article">17</ref-type><contributors><authors><author>Allen, D. </author><author>Channon, S, </author><author>Lowes, L. </author><author>Atwell, C. </author><author>Lane, C. </author></authors></contributors><titles><title>Behind the scenes: the changing roles of parents in the transition from child to adult diabetes service</title><secondary-title>Diabetic Medicine</secondary-title></titles><periodical><full-title>Diabetic Medicine</full-title></periodical><pages>994–1000</pages><volume>28</volume><dates><year>2011</year></dates><urls></urls></record></Cite></EndNote>]] highlight that provision for parents is withdrawn at the time they need it most.

Intervention studies remain limited. One paper reporting the development and evaluation of a peer support group for parents of young people with health conditions transitioning to adulthood [{ ADDIN EN.CITE <EndNote><Cite><Author>Kingsnorth</Author><Year>2011</Year><RecNum>4539</RecNum><DisplayText><style face="superscript">63</style></DisplayText><record><rec-number>4539</rec-number><foreign-keys><key app="EN" db-id="exwx9f9epzvv52ezrvippa79z22d9pawfes" timestamp="1452691937">4539</key></foreign-keys><ref-type name="Journal Article">17</ref-type><contributors><authors><author>Kingsnorth, S. </author><author>Gall, C. </author><author>Beayni, S. </author><author>Rigby, P. </author></authors></contributors><titles><title>Parents as transition experts? Qualitative findings from a pilot parent-led peer support group</title><secondary-title>Child: care, health and development</secondary-title></titles><periodical><full-title>Child: care, health and

development

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2011

found that parents who attended the group gained new knowledge and became more future-oriented and active in their transition preparations. Further research is required to explore the effectiveness of interventions helping parents and young people define and respond appropriately to their shifting roles and responsibilities [ { ADDIN EN.CITE { ADDIN EN.CITE.DATA } }].

Lone consulting for young people remains controversial. Our findings suggest that exclusion from consultations is difficult for parents, particularly when they perceive their child is not coping well [ { ADDIN EN.CITE

<EndNote><Cite><Author>Gannoni</Author><Year>2010</Year><RecNum>4387</RecNum><DisplayText><style face="superscript">12</style></DisplayText><record><rec-number>4387</rec-number><foreign-keys><key app="EN" db-id="exwx9f9epzv52ezrvippa79z22d9pawfes" timestamp="1408362561">4387</key></foreign-keys><ref-type name="Journal Article">17</ref-type><contributors><authors><author>Gannoni, A. F. </author><author>Shute, R. H. </author></authors></contributors><titles><title>Parental and child perspectives on adaptation to childhood chronic illness: A qualitative study</title><secondary-title>Clinical Child Psychology and Psychiatry</secondary-title></titles><periodical><full-title>Clinical Child Psychology and Psychiatry</full-title></periodical><pages>39–

53</pages><volume>15</volume><number>1</number><dates><year>2010</year></dates><urls></urls></record></Cite></EndNote> }]. While professionals have shown empathy for parents' information needs, a belief that parents gradually lose their right to information about their young adult child's health is embedded in practice [ { ADDIN EN.CITE

<EndNote><Cite><Author>Iles</Author><Year>2010</Year><RecNum>4532</RecNum><DisplayText><style face="superscript">53 59</style></DisplayText><record><rec-number>4532</rec-number><foreign-keys><key app="EN" db-id="exwx9f9epzv52ezrvippa79z22d9pawfes" timestamp="1452529616">4532</key></foreign-keys><ref-type name="Journal Article">17</ref-type><contributors><authors><author>Iles, N. </author><author>Lowton, K. </author></authors></contributors><titles><title>What is the perceived nature of parental care and support for young people with cystic fibrosis as they enter adult health services?</title><secondary-title>Health and Social Care in the Community (2010) 18(1), 21–29</secondary-title></titles><periodical><full-title>Health and Social Care in the Community (2010) 18(1), 21–29</full-title></periodical><pages>21–

29</pages><volume>18</volume><number>1</number><dates><year>2010</year></dates><urls></urls></record></Cite><Cite><Author>Doyle</Author><Year>2015</Year><RecNum>4540</RecNum><record><rec-number>4540</rec-number><foreign-keys><key app="EN" db-id="exwx9f9epzv52ezrvippa79z22d9pawfes" timestamp="1452692654">4540</key></foreign-keys><ref-type name="Journal Article">17</ref-type><contributors><authors><author>Doyle, M. </author><author>Werner-Lin, A. </author></authors></contributors><titles><title>That eagle covering me: transitioning and connected autonomy for emerging adults with cystinosis</title><secondary-title>Pediatric Nephrology </secondary-title></titles><periodical><full-title>Pediatric Nephrology</full-title></periodical><pages>281–

291</pages><volume>30</volume><dates><year>2015</year></dates><urls></urls></record></Cite></EndNote> }]. However, this issue is complex; while lone consulting is cited as a common goal in





theories [{ ADDIN EN.CITE { ADDIN EN.CITE.DATA }}] and in keeping with international policy studies suggesting the need for system-level transition strategies [{ ADDIN EN.CITE <EndNote><Cite><Author>Hepburn</Author><Year>2015</Year><RecNum>4564</RecNum><DisplayText><style face="superscript">67</style></DisplayText><record><rec-number>4564</rec-number><foreign-keys><key app="EN" db-id="exwx9f9epzvv52ezrvippa79z22d9pawfes" timestamp="1458036051">4564</key></foreign-keys><ref-type name="Journal Article">17</ref-type><contributors><authors><author>Hepburn, C. M.</author><author>Cohen, E.</author><author>Bhawra, J.</author><author>Weiser, N.</author><author>Hayeems, R. Z.</author><author>Guttmann, A. </author></authors></contributors><titles><title>Health system strategies supporting transition to adult care.</title><secondary-title>Archives of Disease in Childhood</secondary-title></titles><periodical><full-title>Archives of Disease in Childhood</full-title></periodical><pages>559–564</pages><volume>100</volume><number>6</number><dates><year>2015</year></dates><url s></urls></record></Cite></EndNote>}}]. The finding that parental perceptions of the child's condition and abilities guide their willingness to transfer responsibility for condition management to young people further indicates utility of the Common Sense Self-Regulation model in which health behaviour is theorised to be guided by cognitive and emotional illness perceptions [{ ADDIN EN.CITE <EndNote><Cite><Author>Leventhal</Author><Year>1980</Year><RecNum>13</RecNum><DisplayText><style face="superscript">68 69</style></DisplayText><record><rec-number>13</rec-number><foreign-keys><key app="EN" db-id="exwx9f9epzvv52ezrvippa79z22d9pawfes" timestamp="1325763879">13</key></foreign-keys><ref-type name="Book Section">5</ref-type><contributors><authors><author>Leventhal, H.</author><author>Meyer, D.</author><author>Nerenz, D. </author></authors><secondary-authors><author>Rachman, S. </author></secondary-authors></contributors><titles><title>The common-sense representations of illness danger</title><secondary-title>Medical Psychology</secondary-title></titles><pages>7–30</pages><volume>2</volume><dates><year>1980</year></dates><pub-location>New York</pub-location><publisher>Pergamon</publisher><urls></urls></record></Cite><Cite><Author>Leventhal </Author><Year>2003</Year><RecNum>169</RecNum><record><rec-number>169</rec-number><foreign-keys><key app="EN" db-id="exwx9f9epzvv52ezrvippa79z22d9pawfes" timestamp="1374057462">169</key></foreign-keys><ref-type name="Book Section">5</ref-type><contributors><authors><author>Leventhal, H.</author><author>Brissette, I. </author><author>Leventhal, E. </author></authors><secondary-authors><author>Cameron, L. D.</author><author>Leventhal, H.</author></secondary-authors></contributors><titles><title>Self-regulation of health and illness</title><secondary-title>The Self-Regulation of Health and Illness Behaviour</secondary-title></titles><dates><year>2003</year></dates><pub-location>London</pub-location><publisher>Routledge</publisher><urls></urls></record></Cite></EndNote>}}]. Parents have been shown to hold representations of their child's condition and treatment which influence their behaviour regarding healthcare professional advice [{ ADDIN EN.CITE <EndNote><Cite><Author>Klok</Author><Year>2011</Year><RecNum>4542</RecNum><DisplayText><style face="superscript">70</style></DisplayText><record><rec-number>4542</rec-number><foreign-keys><key app="EN" db-id="exwx9f9epzvv52ezrvippa79z22d9pawfes" timestamp="1452701702">4542</key></foreign-keys><ref-type name="Journal Article">17</ref-type><contributors><authors><author>Klok, T.</author><author>Brand, P. L.

</author><author>Bomhof-Roordink, H.</author><author>Duiverman, E. J.  
</author><author>Kaptein, A. A.</author></authors></contributors><titles><title>Parental illness  
perceptions and medication perceptions in childhood asthma, a focus group  
study</title><secondary-title>Acta Pædiatrica</secondary-title></titles><periodical><full-title>Acta  
Pædiatrica</full-title></periodical><pages>248–  
252</pages><volume>100</volume><number>2</number><dates><year>2011</year></dates><url  
s></urls></record></Cite></EndNote>}}. Parental self-efficacy beliefs about their capacity to change  
and effect change in their child's self-care behaviours is likely to be central to the success of  
interventions, as suggested by Social Cognitive Theory [{ ADDIN EN.CITE  
<EndNote><Cite><Author>Bandura</Author><Year>1997</Year><RecNum>4</RecNum><DisplayTe  
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type></contributors></authors></contributors><titles><title>Self efficacy: The exercise of  
control</title></titles><dates><year>1997</year></dates><pub-location>New York</pub-  
location><publisher>W.H. Freeman</publisher><urls></urls></record></Cite></EndNote>}}.  
Theories of learning such as Social Development Theory [{ ADDIN EN.CITE  
<EndNote><Cite><Author>Vygotsky</Author><Year>1978</Year><RecNum>4423</RecNum><Displ  
ayText><style face="superscript">72</style></DisplayText><record><rec-number>4423</rec-  
number><foreign-keys><key app="EN" db-id="exwx9f9epzvv52ezrvippa79z22d9pawfes"  
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type></contributors></authors></contributors><titles><title>Mind in society: The development of higher  
psychological processes </title></titles><dates><year>1978</year></dates><pub-  
location>Cambridge, Mass</pub-location><publisher>Harvard University  
Press</publisher><urls></urls></record></Cite></EndNote>}} could also be applied, particularly the  
idea that learning self-management skills occurs during the interaction between individuals and  
more knowledgeable others (e.g. parents or professionals), and that the range of skill that can be  
developed with adult guidance exceeds that which can be attained alone.

A strength of this review is that by consolidating qualitative findings from diverse LTCs, we were able  
to identify a range of common experiences and needs of parents in dealing with a child's increasing  
autonomy acquisition, which may not otherwise have been identified had a disease specific  
approach been taken. These findings indicate the need for transitional care interventions which  
address the needs of parents as well as young people. That only small differences between  
conditions were found, suggests that the issues parents experience during their child's healthcare  
transition are generic. This aligns with existing research and suggests the utility of non-disease  
specific interventions [{ ADDIN EN.CITE { ADDIN EN.CITE.DATA }}]. A limitation of this review is that  
even though our definition of young people was broad, searches still identified papers discussing  
healthcare transition from the perspective of parents of children who fell outside of our specified  
age range [{ ADDIN EN.CITE  
<EndNote><Cite><Author>Doyle</Author><Year>2013</Year><RecNum>510</RecNum><Prefix>e.g  
. </Prefix><DisplayText>e.g. <style face="superscript">62 75</style></DisplayText><record><rec-  
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## 4.2 Conclusion

Parents can be key facilitators of their child's healthcare transition, supporting and encouraging them to become experts in their own condition and care. To do so, parents require clarification on their role and support from service providers. Healthcare practitioners need to work in partnership with parents, in order to help them to facilitate their child's transition, and to maintain their own psychological wellbeing during a stage of parenting that is characterised by ambiguity, uncertainty and risk.

## 4.3 Practice Implications

### 4.3.1 Supporting parents to facilitate their child's transition

Findings suggest that parents can be key facilitators of their child's move toward healthcare independence. Rather than being excluded from the transition process, parents can be assets/resources for supporting the child's adaptation to self-care. Parents, as well as young people, therefore should be supported by health professionals and their needs addressed within transitional

care interventions. Particular attention should be given to incorporating parents' helpful insights about their child and their child's condition, as well as clarifying and supporting them in their changing role. Healthcare providers could work more effectively with parents to facilitate young person autonomy, by introducing families to the concept of "inter-dependency" and supporting them to practice a partnership approach which incrementally engages the young person in developmentally appropriate self-care. Strategies for supporting parents to facilitate their child's transition might include encouraging parents to identify or create opportunities to witness their child's capacity to be responsible for their healthcare; working with families to establish helpful condition management routines, systems and structures, and teaching parents to guide and supervise adolescents in their efforts to self-care; explaining the rationale for developmentally appropriate care (including lone consulting) and negotiating ways of feeding back to parents; teaching parents how to help their child to advocate for themselves (e.g. practising asking questions, modelling communication skills).

#### 4.3.2 Supporting parents through their own transition

Findings further indicate that parents are required to go through their own transition process, from parenting a child to parenting a young adult with a LTC. Parental thoughts, feelings and behaviours regarding such change will inevitably impact on their acceptance of, and adaptation to a new role. Particularly anxious parents who overestimate the risks associated with young person autonomy for example, may be reluctant to relinquish control of their child's condition, leading to them practicing extreme levels of vigilance and protectiveness. This can be perceived as 'problematic' by professionals. However, these parents could be supported through their own transition by healthcare staff working with them to identify particularly anxiety provoking situations and teaching adaptive coping skills. Offering brief psychological interventions individually or in peer/parent support groups would convey sensitivity to the difficult and potentially distressing nature of transition for parents, as well as provide education and support. This would benefit parents who may be at risk of experiencing high levels of anxiety concerning "letting go" of established roles and responsibilities. For parents who are particularly distressed, referral to psychology services may be warranted.

#### 4.3.3 Providing effective transitional care

Findings demonstrate that transitional care arrangements should be in place for parents and young people endeavouring to concurrently assume greater responsibility for self-care with transferring to an unfamiliar healthcare setting, regardless of their condition. While childhood chronic illnesses vary in clinical characteristics and treatment regimens, it is clear that transition issues are not unique to particular disease processes, but are shared among young people with LTCs and their parents. There may be scope therefore for generic transition programmes that address the needs of parent as well as young people and can be tailored to specific conditions. The current state of inadequate transitional care increases the need for a level of parental involvement which undermines the concept of healthcare transition. It further places significant burden on parents, increases perceived differences between paediatric and adult sectors and emphasises the impact of those changes on both parents (e.g. discontinuity of information) and young people (e.g. fewer resources).

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